

The Michigan FAS Web



*"When spider webs unite they can tie up a lion."
~African Proverb~*

Mott Children's Health Center's Chronic Illness / FAS Services

Mott Children's Health Center's Multi-Specialty Chronic Illness Clinic became operational in March 1998 upon approval from the Michigan Department of Community Health (MDCH) to implement these Children's Special Health Care Services (CSHCS) subspecialty services. The Clinic provides local access to multidisciplinary services to children with chronic illness or complex needs.

MDCH awarded Mott Children's Health Center (MCHC) a grant in May 1999 to establish a Fetal Alcohol Syndrome (FAS) Center of Excellence. This Center was integrated with the health center's Chronic Illness Clinic. The goal of the integrated clinic is to diagnose and provide families with referrals, resources and recommendations for managing and coordinating the care of their child. Services include screening, evaluation, diagnosis, and service coordination.

The clinic currently meets on the third Wednesday of the month and can assess six children each month. MCHC's multidisciplinary team consists of two pediatricians, registered nurse (RN), psychologist, social worker (SW), and speech pathologist. In addition, an occupational therapist from Hurley Children's and Family Rehabilitation and a registered dietitian from Genesee County-Michigan State Extension also provide assessments. The six multidisciplinary core team members received specialized FAS training in Seattle.

Once a referral is received, the R.N. or S.W. contacts the family and completes the prescreen. If the child

is eligible, a home visit is scheduled to complete the screening process and obtain additional information. A family questionnaire is completed which includes past and present information regarding the child's physical and mental health, behavioral concerns, school progress, and social functioning. Previous records are requested and reviewed, and necessary assessments are scheduled. Assessments done prior to clinic include hearing, speech, and psychological (including neuro-psych). Once these assessments are completed, a clinic date is scheduled. At the clinic, additional assessments – including physical examination, height, weight, and head circumference - dietary and occupational therapy assessment are done and a diagnosis is made. A case conference is held with the family to inform them of the diagnosis, findings, and recommendations for further care, as well as to answer their questions, including their input in their child's plan of care.

A parent facilitator meets with families in clinic and also assists families with accessing available resources. A copy of the assessments, recommendations, and plan of care are provided to the family soon after clinic by the R.N. or S.W. in another home visit. Follow-up phone calls are made six months after clinic to determine current status and assess the need for further intervention. Additional short-term service coordination is provided to families in need.

MCHC also facilitates the Genesee County FAS Community Advisory Coalition, comprised of a broad variety of community agencies as well as the

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Creative Awareness Techniques: Tips from the Northeast

The Northeast Michigan Community Partnership has been involved in a Fetal Alcohol Syndrome project for 4 years. The initial project focused on placing warning signs and labels in all establishments licensed to sell alcohol in Alcona, Alpena, Montmorency and Presque Isle counties. Since that time the project has expanded to a multi-faceted effort to prevent FASD and provide support for families who are already struggling with the consequences of prenatal alcohol exposure.

A twenty-five member Task Force helps guide the project and serves as a 'think tank' to determine the best methods to accomplish our objectives. Members often talk about the need for persistence and patience, as all would like to see immediate progress, but know that community change is a long-term effort. The largest challenge has been fully engaging the medical community in prevention, and support for families during the screening and diagnostic process.

Educational presentations are made to students, teachers, agency staff and community groups. Brochures are distributed with prenatal vitamins and birth-control prescriptions at pharmacies. Information is shared at prenatal classes. Churches who provide premarital counseling share printed materials. Churches and worksites distribute printed materials. Displays are set up at malls, county fairs and health fairs.

A support group meets twice monthly to share successes and challenges. The facilitator is an adoptive parent of a FAE child, now an adult, with many years of experience leading parent groups. It is a privilege for the project coordinator to sit in on these meetings and is an invaluable learning experience.

Community Partnership has developed several unique projects to bring awareness of FASD to the community. In November and December Community Partnership staff goes on the road with hot punch, distributing alcohol-free beverage recipes, information on FASD and hosting alcohol-free parties.

The idea for a mock "Baby Shower" was borrowed from a California project. Items typically found at a baby shower were purchased and packed in gift bags. Each bag contains a description of a possible effect that relates to the object. The "Baby Shower" is used as part of presentations to various groups and allows the audience to participate. A visual display using beads compares the occurrence of FASD to other better-known childhood birth defects.

A visual display has also been developed using stick people built by students in the Turning Point program, an alternative education setting for adjudicated youth. The stick people are 18" to 24" high and represent in a graphic manner the number of people liv-



ing in the community who have FAS or FAE. Since most cases go undiagnosed, the numbers were generated by using the prevalence calculator developed by Larry Burd, Director of the North Dakota FAS Center. The prevalence calculator is available at <http://online-clinic.com/>. People in the best position to have a realistic picture of the prevalence of FASD consider these figures to be conservative. This visual display has generated much more interest than other displays we have used in the past. The intention is to set up the display in any area with high foot traffic. The goal of bringing attention to the number of individuals with FASD is to help the community know this issue needs to be taken seriously, and to encourage people who are in this situation to know they are not alone and perhaps be more comfortable in asking for help.

For more information, contact Mary Schalk, (989) 734-2877 or schalkaero@lhi.net

Living and Learning with FAS/ARND

First Ever Conference By and For Individuals with FAS/ARND

For years, Barbara Wybrecht had a vision, an opportunity for individuals with FAS/ARND to get together and have their own conference. This conference had to be different though. It would not only be planned *for* individuals with FAS/ARND but it would be planned *by* these individuals. On August 15, 2002, that vision became a reality. The planning committee, over half of which have FAS/ARND, were delighted to see their year long efforts of planning and coordinating paying off as forty-five conference attendees and forty-five support persons arrived at Camp Henry in Newaygo, Michigan.

Participants came from all over the United States. In all, 11 states were represented ranging from Ohio to California and Alaska to Texas. In addition, several participants came from Canada. For some of the attendees this conference was the first time they had ever met another person with FAS/ARND.

Nationally known researchers and leaders in the field provided presentations and workshops at the cognitive and interest level of the participants. Presenters included:

- Ann Streissguth PhD, University of Washington
- Ed Riley PhD, San Diego State University
- Faye Calhoun PhD, National Institute on Alcohol Abuse and Alcoholism
- Jacquelyn Bertrand PhD, Centers for Disease Control and Prevention
- Karen Stern, PhD, Office of Juvenile Justice
- Karla Damus PhD, National March of Dimes
- Marsha Katz, Rural Institute, University of Montana

Workshop sessions were led by affected individuals

themselves or in tandem with their support person or a professional. Topics included:

- Sharing My Good Ideas About Living with FAS
- What to Do if You Are Stopped by the Police
- Job Success – What Helps and What Hurts?
- What to Do with the Mad that You Feel?

All conference attendees participated in the session entitled, “We Can Prevent FAS.” Following this they broke into small groups and created a preven-

tion skit or practiced one previously developed and selected by their group. Skits were videotaped so that the message could be reinforced after they returned home. Some groups also presented their skit to the entire conference on Saturday evening.

In addition to the educational sessions, participants were able to take part in social and recreational activities including swimming, boating, horseback riding, line dancing, drumming, campfires and singing.

Evaluations were both glowing and touching. One young person stated that he did not want to go home as, “This is the one place where everyone understands me.” Others were thrilled to have made new friends as they don’t have friends at home. One parent wrote, “I can’t tell you how much I grew that weekend. The knowledge we received will be there for us forever. Accepting and understanding what’s in store for our daughter and us as a family, was the greatest gift we received and we thank you.”

It is hoped that this pilot conference will be replicated regionally throughout the United States and also in Canada.

“Happy Campers”



Ann Streissguth and Rob Wybrecht

Websites you don't want to miss...

www.come-over.to/FASCRC

This is an amazing site with information galore. Teresa Kellerman manages the site and posts articles and links on a huge range of information, including:

- ★ basic FAS information
- ★ practical information for families
- ★ research updates
- ★ resources

www.mofas.org/fasdirect

This site connects to the national FAS directory. This directory is being maintained by Jodee Kulp who has graciously committed herself to keeping the directory as current and accurate as possible. Check out the links in Michigan to make sure your information is accurate and also use this resource to make referrals for those from other communities. If you find any information that needs to be added or changed in the directory, contact jodee@connetworks.com

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Parent Support Group. Education is provided to families and providers, and community awareness activities are implemented regarding the prevention and early identification of FAS.

Referrals for MCHC FAS services are accepted for children in Genesee County. A limited number of referrals are accepted from other counties in Michigan. Referrals may be made by anyone. The majority of referrals come from agencies and other professionals, followed by parents or caregivers. Because of the demand for services, there is a waiting period of approximately 3 months from the time of referral until the clinic date. During this waiting time, families are referred to the Parent Support Group and any other services that are indicated. The RN and SW are also available for support and assistance during this time period. Referrals can be made by calling (810) 237-7572.

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